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# Supporting Self-Care of Adolescents with Nut Allergy Through Video and Mobile Educational Tools

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## ABSTRACT

Anaphylaxis is a life-threatening allergic reaction which is rapid in onset. Adolescents living with anaphylaxis risk often lack the knowledge and skills required to safely manage their condition or talk to friends about it. We designed an educational intervention comprising group discussion around videos of simulated anaphylaxis scenarios and a mobile application containing video-based branching anaphylaxis narratives. We trialed the intervention with 36 nut allergic adolescents. At 1-year follow-up participants had improved adrenaline auto-injector skills and carriage, disease- and age-specific Quality of Life and confidence in anaphylaxis management. At 3-year follow-up adrenaline carriage improved further and confidence remained higher. Participants expressed how the education session was a turning point in taking control of their allergy and how the app facilitated sharing about anaphylaxis with others. We contribute insights regarding design of mobile self-care and peer-support applications for health in adolescence, and discuss strengths and limitations of video-based mobile health interventions.

## Author Keywords

Adolescents; anaphylaxis; health; food allergy; patient education; mixed methods; video; mobile health.

## ACM Classification Keywords

J.3. Life and Medical Sciences: Health; H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

## INTRODUCTION

Food allergy occurs when the immune system responds to food inappropriately and causes adverse health effects [60]. Food allergy is common, with almost 6% of Europeans reporting that they are allergic to one or more foodstuffs (half

of these have convincing symptoms and test results) [43]. Symptoms of food allergy can include tingling of the mouth, rashes, swelling and more severe reactions. Anaphylaxis is a severe, potentially life-threatening allergic reaction that is rapid in onset and may cause death through airway, breathing or cardiovascular collapse [42]. Anaphylaxis prevalence is estimated at 0.3% in Europe [49] and up to 1.6% in the US [75], suggesting over 2 million Europeans and 5 million Americans are affected. Rates of anaphylaxis are increasing, with a 615% rise in hospital admissions for anaphylaxis in the United Kingdom over a 20-year period. Fatal food-triggered reactions peak in the second and third decades of life [68]. Those living with anaphylaxis risk must vigilantly avoid triggers to a severe reaction (allergens) [20], but accidental exposures may occur [44]. Prompt and effective administration of adrenaline using an auto-injector device is a key step in management of reactions [56]. However, gaps in the education and self-care of those living with anaphylaxis can lead to reactions and, in the severest of cases, death, with adolescents at particular risk [10, 42].

In recent years there has been a surge in interest in the potential for mobile applications to support people in the management of health conditions [1, 8, 28]. This has been equally so for food allergy, with prior work exploring apps to support food journaling practices [5, 14], meal decision making [32] and to identify allergen friendly eateries [26]. However, little research has addressed the role of technology as a preventative and educational measure for those with food allergy. Research in this space is even sparser in relation to adolescence, which is surprising given the specific risks of this age group [10, 54]. As such, with increasing ownership of smartphones among this age group [45, 47], mobile interventions could play an important role as part of educational programmes and self-care practices.

In this paper we report on the evaluation of React, an educational intervention that was part group session, part mobile application. React used video-based anaphylaxis narratives to illustrate to young people that different self-management choices may have different consequences. We conducted a study of React with 36 nut allergic adolescents, each of whom participated in an initial group session and were provided the React mobile application to use in their



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daily lives. We conducted pre and post (at 3–4 and 12 month) measures for quality of life, anaphylaxis knowledge and skills in the use of auto-injector devices. Additionally, we conducted pre and post measures of confidence around allergy management and carriage of auto-injectors (at 3–4, 12 and 36 months). We conducted focus groups (at 30 months) and individual interviews (at 37 months). We offer two contributions to HCI research. First, we highlight the potential that mobile educational packages have for improving self-care and management around potentially life-threatening health conditions. Second, we demonstrate how video can be used as a tool for reinforcing age-appropriate education for adolescents with chronic illnesses which, when combined with mobile platforms, can support the sharing of knowledge with peers to support healthy practices.

## BACKGROUND

The World Health Organization defines adolescence as the period between childhood and adulthood, from 10 to 19 years of age [76]. Adolescence is a critical phase in human development, characterised by rapid growth, biological and psychosocial changes [76]. Outcomes for long-term health conditions are poorer in adolescence than in childhood and adolescents are high users of health services [17, 73]. Self-management behaviours for long-term conditions are largely initiated during adolescence [58]. Individuals take over management of such conditions from their parents during adolescence and there is evidence that patterns of health behaviours established during adolescence are maintained through adult life [55]. Adolescence is thus an important period to influence the trajectories of health conditions throughout later life [17]. However, adolescents remain an unusually under-researched population in healthcare and age-appropriate services remain lacking [17, 55].

Food allergy affects an estimated 2.3% of adolescents, with peanut and tree nuts the most frequent triggers [51]. A recent estimate [72] suggests that there are now over 11 times more anaphylaxis episodes reported in adolescents than there were in the 1990s [20]. Living with food allergy and anaphylaxis risk has a profound impact on the quality of life and psychological distress of adolescents [4, 15]. The need to be constantly aware of avoiding triggering foodstuffs impacts on daily life and activities. Emotional quality of life [21, 52] and quality of school life [36] are also known to be adversely affected, with food allergic schoolchildren twice as likely to be bullied as their non-allergic peers [41].

The health and care literature notes important self-care strategies for adolescents who have nut allergy and who are at risk of anaphylaxis. Diligent avoidance of the nuts (and other triggers) that they are allergic to is the first stage of avoiding a reaction. However, nuts are frequently found in foods that are consumed socially and inadvertent exposure can occur [44]. In the event of an allergic reaction it is essential that an individual promptly identifies that they are having a reaction, how severe that reaction is and what treatment is most appropriate. Mild reactions are treated with

antihistamines; symptoms of wheeze or shortness of breath require inhaled bronchodilators; whereas severe symptoms suggestive of anaphylaxis require prompt administration of adrenaline via an auto-injector device. These steps of avoidance, recognition of and response to reactions formed the basis of the educational package described herein.

However, evidence suggests that adolescents at risk of anaphylaxis are not adequately equipped to follow these self-care steps. Gallagher et al. highlighted that, despite receiving training by allergy specialists in clinic, adolescents remain inadequately prepared for anaphylaxis emergencies [24]. Issues included adolescents not carrying adrenaline at all times; failing to identify anaphylactic reactions; not knowing when to use adrenaline and inability to demonstrate correct administration of adrenaline [24]. It is of note that similar issues are found to be causes of deaths from anaphylactic reactions (e.g. adrenaline used too late in reaction; adrenaline not carried at time of reaction) [10, 54]. Monks et al. observed that adolescents demonstrate risk-taking behaviour when managing food allergies, which may contribute to their increased anaphylaxis mortality [38]. Such behaviours included intentional consumption of food that may have contained their triggering allergens and non-carriage of adrenaline. Additionally, Monks et al. describe how adolescents wish that their classmates and peers were more aware or educated about their allergies, as this would make allergy management simpler and risk taking less likely. The adolescent participants also felt that education that was frank about the consequences of a reaction would be helpful, perhaps using films of what happens during a reaction.

Given these challenges, effective educational strategies are required to address this population's gaps in self-care skills and behaviours and to potentially improve their quality of life. Kirk et al. reviewed self-care interventions for children and young people with a variety of chronic health conditions and reported that interventions that were group-based or involved technology were associated with improved knowledge and well-being [34]. Jones et al. demonstrated a correlation between good adherence to self-care behaviours and having a written anaphylaxis management plan or being a member of a patient support group [33]. However, only 41% of Jones' cohort reported carrying their adrenaline auto-injector at all times. While further interventions have been trialled, they target parents and carers of affected children or adults with allergies, not affected adolescents [12, 61, 70].

Thus, adolescents living with anaphylaxis risk often lack the knowledge and skills to safely manage their condition. This is a crucial time in their development, as they transition from parental control to self-care. Current education is inadequate and interventions target parents of children with allergies or adults living with anaphylaxis risk, but not adolescents themselves. Our research aims to address this gap.

## Mobile Health and Allergy in HCI

Smartphone and mobile application use among teenagers and young adults has grown rapidly in western countries, now

reaching 85% in the US [45] and 90% in the UK [48]. The general proliferation in ownership of smartphones has been accompanied by interest in supporting the health of users through apps targeting specific conditions and care practices [1, 8, 28]. This provides an opportunity to explore how mobile-based interventions could be used to deliver health education and self-care support to young people with chronic health conditions [65, 74]. Indeed, young people use health information websites, social media and health apps as important sources of information and these have potential to modify their health behaviours [39, 62]. The short-term utility of mobile apps in clinical management has been demonstrated for adolescents with health conditions such as diabetes, with gamification of blood glucose measurements leading to improved frequency of measurements [13] and photo-based food diaries helping young people to better visualize important self-care strategies [23]. Similarly, there is great potential for mobile technology to support positive self-care behaviours in those living with anaphylaxis risk. However, regulators and clinicians require such technology to deliver lasting clinical benefit [35] and evidence is lacking for the long-term impact of many health applications [1, 28].

In the specific area of food allergy there is prior work exploring the role technology may play in a number of contexts. Prototype apps and models have been proposed to detect and warn users about the risk of ingesting foods that they are allergic to using situation awareness [18]; to assist those with dietary restrictions make safe meal choices [32]; and to match user's requirements to suitable restaurants [16]. Such automated systems could potentially alleviate some of the burden of constant vigilance that those with severe allergies live with, however, these systems have not yet led to consumer products and have not been trialled in real-world settings by people with allergies. Others have examined the potential of smartphone-based food diaries, demonstrating they can make it easier to capture what users or their children eat [14, 30] and to aid in the diagnosis of food allergy [5, 69]. One important design insight from such work is that it is crucial that such technology is simple to use and does not become an additional burden to families and individuals already living with considerable stress due to their allergies [30]. The "Anaphylaxis" app was developed by Anderson et al. and constitutes a digital version of a written anaphylaxis management plan [2]. Users enter details of their allergies and medication and the app contains written information about anaphylaxis symptoms and emergency response. Finally, Garbett et al. describe the NutFree app in one of the case studies of their App Movement paper [26]. Developed with people living with allergies, NutFree supports users in both searching for and providing their own location-based reviews of the nut allergy friendliness of restaurants. However, while all of these offer great potential, there has been no testing of implementation of these apps or assessment of their effectiveness. Furthermore, none of these explicitly address issues related to educational support.

### Video as an Educational and Support Tool

Compared with other educational media, interventions using video have been shown to be effective at modifying health behaviours, particularly when focusing on what can be gained from complying with recommended self-care [67]. Interactivity in video-based learning can enhance the learning experience [19]. Video has been shown to enhance knowledge and promote improved self-care in health fields as diverse as sunscreen use [6]; treatment decision making in skin cancer [37]; and sexually transmitted disease and attitudes towards condoms [9]. In particular, Armstrong highlights that video-based learning is more effective than written materials and may be particularly useful for learning new concepts or practical techniques [6]. There are no published video-based interventions for adolescents with allergy. Previous work has identified that adolescents do not find written information as helpful as others do [25]. Video may offer an age-appropriate solution to this. Video has been used in interaction design with adolescents to empower young people to participate in HCI research and as a means of accessing adolescents' everyday lives [53]. Other work has shown that video (health vlogs) can help develop social support for those with chronic diseases through intimate personal connection and the flexibility of the medium [31].

### Summary

Despite the work to date in health, care and HCI literature, there are still no interventions described in the field of allergy that demonstrate long-term impact on the knowledge, skills or self-care behaviours of those living with anaphylaxis—either in general, or adolescents in particular. Video and mobile technology have the potential to address gaps in both the literature and in the care of these young people.

### DESIGNING THE REACT INTERVENTION

In this research we were interested in exploring novel education for adolescents with nut allergy who were living with the risk of anaphylaxis. Our design process involved an interdisciplinary team including a consultant paediatric allergist; a paediatrician with interests in allergy and adolescent health, a team of interaction design researchers (one of whom lives with severe nut allergy) and film makers.

The Health Belief Model suggests that to effect change we must ensure that individuals recognise that they are susceptible to a health problem which is serious (perceived threat) and believe that there is a benefit to following a particular course of action (outweighing any barriers) that will reduce the perceived threat [57]. This model was used in the development of the intervention.

Drawing on the evidence presented above, personal and clinical experience, we developed a two-stage intervention involving: (i) a short peer group education session in which videos of simulated anaphylaxis scenarios would be shown to prompt discussion; and (ii) a smartphone application to continue providing education beyond the single session and share information with participants' friends and families.



**Figure 1 – An example storyboard from the development of the anaphylaxis scenario videos, demonstrating decision points and branching outcomes (indicated by arrows).**

### Videos of Simulated Anaphylactic Reactions

The anaphylaxis scenarios reflect likely situations in which young people might be inadvertently exposed to nuts, involving the consumption of food in social settings (perceived threat). Two scenarios were scripted for friends going to the cinema and to a café. In each scenario the young person experiencing an anaphylactic reaction was uncertain how to manage the reaction and their friend was a supportive influence, showing concern and prompting them to use appropriate treatment. Scripts were designed to offer narrative branch points at which decisions made by the protagonists would lead to different outcomes (e.g. recognizing reaction was severe or not; using antihistamine treatment or adrenaline treatment) (see Figure 1).

Once completed, the scripts were filmed using young actors from a local theatre company. All possible permutations of each scenario were filmed so that an interactive branching narrative could be created. Videos were then overlaid with animations illustrating symptoms that young people watching the videos should watch out for (e.g. dizziness, shortness of breath) and treatment steps (e.g. correct way to hold adrenaline auto-injector and site to administer it). These animations were designed in a comic book style that matched the style used in the React app (see Figure 2). Practical steps were highlighted and ideal behaviour modelled to help participants acquire skills effectively [6]. Positive outcomes from successful management were emphasised to focus on potential gains from appropriate action [57, 67].

### Education Session

The education session was designed around the three critical stages of anaphylaxis self-care: (i) avoidance of allergens, (ii) recognition of allergic reaction and its severity, and (iii) appropriate response to reactions. The education session was designed to be practical to deliver within a single 90-minute session. Throughout the session we encouraged peer interaction and the sharing of personal experiences. While waiting for the session to start, participants completed an ice-breaker activity in which they matched pictures of nuts with their names and shared answers with each other. The React



**Figure 2 – React videos of simulated anaphylaxis scenarios were overlaid with animations to highlight symptoms (e.g. dizziness) and treatment steps (e.g. correct way to hold adrenaline auto-injector and correct delivery)**

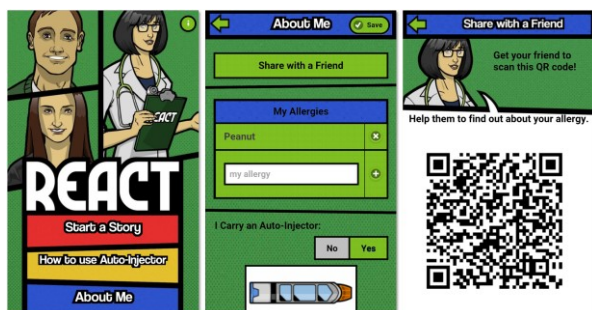
videos were then shown to the group, using scenarios in which the protagonists made mistakes in reaction management. These were used as discussion prompts and again, peer interaction was encouraged. The group were then shown alternative sequences of video in which correct management decisions were made. Subsequently, the group split into 3 and rotated through 3 tasks: (i) nut recognition (food packaging and social situations), (ii) reaction severity and response (including hands-on practice with trainer auto-injector devices), and (iii) an introduction to the React app (encouraged to access app and shown features). The session closed with a check of participants' knowledge and skills.

### Mobile Application

React is a web-based app, compatible with any mobile device with Internet connectivity (i.e. smartphone or tablet). The app is comprised of four main components:

- 1) 'Start a Story' mode incorporates the anaphylaxis scenario videos within an interactive decision-making tool. Choices made by users determine the outcome of each scenario and include recognition of the severity of the reaction and specific steps in auto-injector use. The narrative branches depending on user choice, leading to numerous potential outcomes. Following the Health Belief Model [57], the branching narrative aims to enhance adolescents' understanding of clues to the severity of a reaction. By selecting different options on repeated progress through scenarios, users see which actions have beneficial outcomes.
- 2) 'How to use Auto injector' mode, contains training video and animations for different adrenaline devices.
- 3) 'About Me' page, to record allergies and the type of adrenaline auto-injector device that they carry.
- 4) Users can share the app using an app-generated Quick Response Code. This provides a "friend" version of React





**Figure 3 – The React mobile application enables the user to record details about their allergies and share the app with friends and family members using a QR code.**

containing the sharing user's allergy and auto-injector information (see Figure 3), as well as the first two components so that friends and family members can become similarly skilled in recognition and response to reactions.

### FIELD TRIAL

This was a single centre, pre- post-intervention study with long-term follow-up employing quantitative and qualitative methods. Participants were recruited from a paediatric allergy clinic in the UK between November 2012 and July 2013. Participants were aged 11-16 years at recruitment, had clinician-diagnosed peanut and/or tree nut allergy and were prescribed an adrenaline auto-injector for use in the event of anaphylaxis. Participants (and parents/guardians if under 16) gave informed consent to take part in the study. Favourable opinions were received from Research Ethics Committees for both the quantitative and qualitative phases of the study.

### Educational Intervention

Participants attended the education session in groups of up to 9. Participants were free to choose whether to continue to use the React app or not after the education session.

### Quantitative Assessment Measures

A number of measures (anaphylaxis knowledge, auto-injector skill and carriage, disease- and age-specific quality of life and confidence in anaphylaxis management) were made at baseline and at follow-up appointments at 3-4 (FU1) and 12 months (FU2) after the education session. Knowledge and skill were also measured at the end of the education session. Confidence and auto-injector carriage were additionally measured during a survey (postal and electronic) sent to participants 36 months after the intervention.

Anaphylaxis knowledge was assessed using a validated 15-item quiz [61]. Questions related to self-care strategies, recognition of reactions and correct management steps. There were 3 auto-injector devices available to participants at the time of the study (EpiPen®, EpiPen® II (Meda), Jext® (ALK-Abelló)). Auto-injector skill was measured for each device using 7-item checklists based on manufacturers' guidelines on correct device usage. Correct auto-injector administration required: (i) device recognition; (ii) removal of safety cap; (iii) selection of correct injection site; (iv) selection of correct end of device for injection; (v) use of correct injection technique; (vi) holding device in place for

≥10 seconds; and (vii) massaging injection site for ≥10 seconds. Disease- and age-specific quality of life was measured using the validated Food Allergy Quality of Life Questionnaire-Teenager Form (FAQLQ-TF) [22]. This assesses the impact of food allergy on quality of life across three subscales: Allergen Avoidance and Dietary Restriction, Emotional Impact (of food allergy on their quality of life) and Risk of Accidental Exposure. FAQLQ-TF scores range from 1 (minimal impairment in quality of life) to 7 (maximal impairment) [71]. Confidence in anaphylaxis management was rated on a 5-point (140mm) Likert scale. Participants were asked to rate "How confident do you feel about managing a severe allergic reaction (anaphylaxis)?" Self-reported adrenaline auto-injector carriage was reported as "always", "often", "occasionally" or "never".

### Qualitative methods

Questionnaires were completed at FU1 and FU2 including free text responses about auto-injector carriage and app use. Focus groups (FG) were held with participants 30 months after the education session. Purposeful sampling [50] was used to hold one group with those that had identified themselves as React app users at 12-month follow-up and the other with those who did not. Groups had 4 participants in each, lasted 60-90 minutes [29] and explored participants' views about the education session and app and experiences of living with allergy. Initial data analysis assisted in the development of the survey (S) sent to participants at 36 months. The survey included questions about who was in control of their allergy and why; peer relationships and participants' reasons for non-carriage of adrenaline. Data from the survey and focus groups informed the development of an interview schedule. Semi-structured, in-depth interviews (I) were held with 3 participants to explore emerging themes in more depth, more broadly understand the lived experience of being an adolescent with nut allergy and design opportunities around this. Focus groups and interviews were audio recorded and transcribed for analysis.

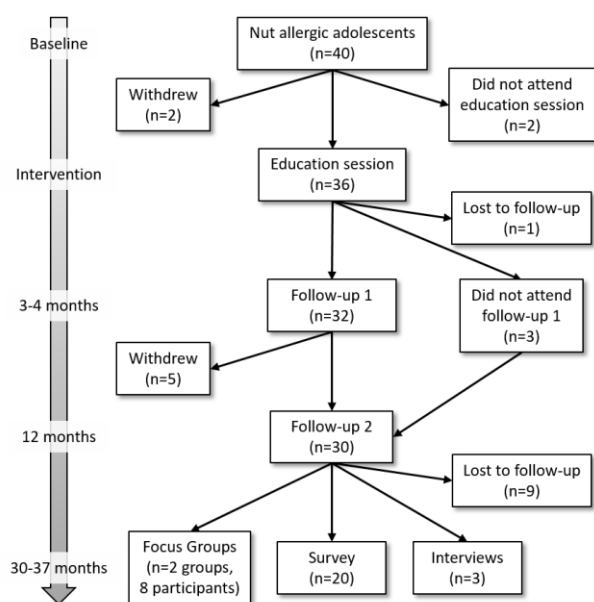
### Analysis

Paired t-tests were used to compare changes over time within groups and un-paired t-tests to compare differences between groups (continuous variables and scale data [46]). Equivalent non-parametric tests (McNemar / chi-square) were used for categorical data. Data were analysed with SPSS v22. A value of  $p < 0.05$  was considered significant.

An inductive thematic analysis was conducted on qualitative data (treating the data as a single corpus), using methods described by Braun and Clarke [11]. Data was read and re-read before coding at the level of sentences to paragraphs (Nvivo v10). Codes were collapsed and modified before drawing out themes from the data.

### Participants

At recruitment there were 40 nut allergic adolescents (19 females), mean age 13.8 years (S.D. 1.5, range 11.1-16.4). Peanut allergy was reported by 34 (85%), tree nut allergy by 26 (65%) and other food allergies by 13 (32.5%). Mean age



**Figure 4 – Flow of participants through study (2 participants withdrew after initial recruitment and a further 2 did not attend the education session).**

at first allergic reaction was 4.8 years (S.D. 3.6, range 0.3–12.0) and 20 (50%) reported a history of anaphylaxis. Figure 4 shows the movement of participants through the study.

## RESULTS

### Quantitative Findings

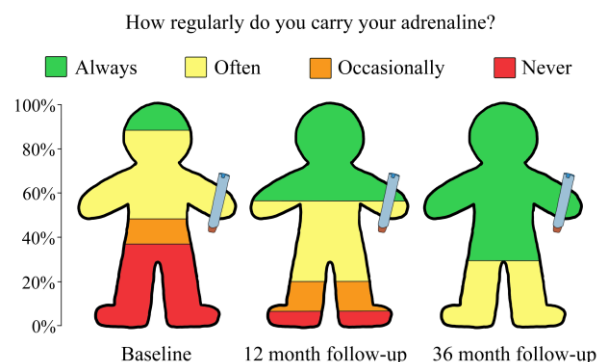
The mean knowledge scores of participants increased after the education session (10.2 (S.D. 2.3) to 11.8 (1.9),  $t=-4.65$ ,  $p<0.001$ ), but fell by FU2 at 12 months, with no significant change from baseline (10.8 (2.2),  $t=1.21$ ,  $p=0.234$ ).

At baseline only 4/40 (10%) participants completed all 7 steps of auto-injector deployment correctly. Mean auto-injector skill score rose after the education session (5.2 (1.0) to 6.3 (0.8),  $t=-5.29$ ,  $p<0.001$ ) and more completed all 7 steps correctly (20/36 (55.6%),  $p<0.001$ ). Mean skill score fell by FU2, but remained significantly better than baseline (5.7 (0.9),  $t=-2.19$ ,  $p=0.037$ ) and 7/30 completed all 7 deployment steps correctly (17.5%).

There was an improvement in quality of life, as shown by a fall in the mean FAQLQ-TF scores of the participants by FU2 (4.2 (1.5) to 3.7 (1.3),  $t=2.25$ ,  $p=0.033$ ). The Emotional Impact subscale showing the largest improvement (4.4 (1.3) to 3.8 (1.1),  $t=2.57$ ,  $p=0.015$ ).

Confidence of the participants rose after the education session (71.2 (35.7) to 116.8 (23.6),  $t=-8.03$ ,  $p<0.001$ ) and remained up compared with baseline at all subsequent time points, including 36-month follow-up (75.0 (35.8) to 103.3 (28.9),  $t=-3.38$ ,  $p=0.003$ ).

At baseline, 5 participants had been prescribed their auto-injector for the first time, so could not comment on their carriage of the device. Of the remaining 35, 4 (11.4%) reported carrying their devices “always”, 14 (40.0%)



**Figure 5 – Adrenaline auto-injector carriage over the study period. Half of the participants reported carrying their device occasionally or never at baseline, with only 11% reporting always carrying it. At 3 years after the education session 70% reported carrying it at all times ( $p<0.001$ ).**

“often”, 4 (11.4%) “occasionally” and 13 (37.1%) “never” (see Figure 5). Over the course of the study the proportion of participants carrying their device “always” increased from 4/35 (11.4%) to 14/20 (70%,  $p<0.001$ ).

### The React App

At FU2, 14 of the 30 participants reported using the React app (46.7%), 10/14 (71.4%) reported that the app was helpful and 11/14 (78.6%) completed the survey at 36 months. Analytic data was limited but indicated the app had been accessed 196 times in the local region by 52 unique users by 12-month follow-up. The extra users may have been those with whom the participants had shared the app. At FU2 app users had better knowledge scores than non-users (users 11.7 (1.6), non-users 10.0 (2.4),  $t=2.29$ ,  $p=0.030$ ). Confidence in anaphylaxis management was greater in app users than non-users at the 36-month survey (users 114.6 (22.6), non-users 89.4 (30.9),  $t=2.10$ ,  $p=0.050$ ).

### Qualitative Findings

Four overriding themes were identified from the qualitative analysis: *taking control*; *individual and shared experiences*; *educating others*; and *risk taking and forgetfulness*.

#### Taking Control

Participants frequently discussed aspects of control related to allergy. Most explained that they felt responsible for being vigilant about potential nut exposures. Checking food they ate was free from nuts was a large part of the burden of living with nut allergy: “I’m always checking, even though some things definitely don’t have nuts in I will still want to check.” (P37, S). Participants were often reluctant to allow others to manage this aspect of living with allergy for them, trusting their own skills over even their parents: “Even family and parents try and do it to me and it still ticks me off. At the end of the day, I will have to read it anyway. I won’t feel safe until I’ve read it.” (P04, I).

Critically important to these young people was that they were experiencing a taking over of control of the management of their condition from their parents. Some shared control over their allergies with their parents and were happy to surrender control to them in particular settings:

*"Over the years it's got more and more my responsibility. I think it's just slowly happened without us even realising that it's happened."* (P21, I)

*"If I'm alone, for example going out with my friends, I have sole responsibility but at home my parents watch what I eat."* (P14, S)

It was clear that this was a two-way process. Parents needed to feel that their child was both competent enough and confident enough to take over control from them:

*"I think my parents mostly [ask about nuts in restaurants], but sometimes they say, 'Oh, you ask, because you need to get the confidence of when you're out on your own to say.'" (P14, FG)*

*"My mum used to nag me quite a lot about making sure I was carrying an Epipen with me [...] but now I'm a bit more independent."* (P31, FG)

Notably, at follow-ups many participants reported that the educational intervention was a turning point for them in them taking control over from their parents. This was, in part, due to it giving them an increased sense of confidence in their knowledge and skills. For example, they found the React videos and app helped sensitise them to potentially risky situations: *"the app was helpful in seeing a potentially real life situation wherein an allergic reaction could occur."* (P09, S). But it was also partly due to their parents feeling that they were better able to self-care:

*"It might actually partially have been due to this [the study], the fact that they know I've been learning about it, and so [my parents] trust me to do more with it, instead of just them having to do that."* (P33, FG)

*"I knew roughly what to do beforehand because it's got it on the Epipen but [the education session] just made me be like, 'Right, okay, I've got this.'" (P21, I)*

The app's branching videos enhanced users' decision-making ability through reflecting on and testing choices in different situations: *"I like the scenarios it gave you and made you decide what to do in certain situations."* (P05, FU1). *"[The app] was good because it taught you what to do."* (P11, FU1). The usefulness of the intervention even led to one participant describing how it had helped her to remotely assist a friend safely through managing their own allergic reaction:

*"[My friend] had a reaction. He was messaging saying, 'I don't know what to do.' And I actually talked him through what to do, and it really helped him. I think that without [the intervention], I wouldn't have had the knowledge of what to do."* (P37, FG).

The process of taking control of one's self-care from parents is a critical transition in growing up with nut allergy. Our participants were given confidence in their own knowledge and skills through this educational package, which seems to have given their parents the green light to let their children take over the day-to-day management of their allergy.

#### Individual and Shared Experiences

Although many participants found the overall intervention helpful, some contested that a "generic" app and series of videos, could not capture the diversity and personal nature of allergies and reactions: *"I think [the videos] were sort of a bit stereotypical, like, of what definitely would happen, because anyone's reaction could be so different."* (P14, FG).

In part, however, it appeared that the concerns around the individualization of allergy was a result of a lack of contact with other people with allergies. Indeed, despite nut allergy being common, the intervention had been the first time many participants had discussed allergies with peers who also had allergies. Prior to this, participants had perceived themselves as isolated or alone and found discussing their issues with those their own age helpful:

*"I remember the videos the most. But I think the best thing was [...] seeing other people the same age as me with allergies because a lot of the time what I find difficult with my allergy is when I'm in public I feel like people won't understand [...] But when I realised there's lots of other people with the allergies it makes me feel a bit more confident about telling people."* (P31, FG)

*"We were with like people of similar age groups who also had similar problems involved in at the same time, it helped me remember a lot more."* (P22, FG)

*"It was better with other people the same sort of age. I think it's easier to remember it when you learn it with other people who are similar to you, than it is when you're [...] one-to-one being shown what to do."* (P33, FG)

During the group sessions the sense that nut allergy was unique to each individual started to break down as participants shared stories and personal experiences. There were a number of specific points of commonality. For example, eating out of the family home was a great source of anxiety and frustration for most participants:

*"I really don't enjoy going to [new restaurants] [...] I'll ask them, 'What can I eat?' and they'll say, 'We can't guarantee,' because that's what most places say [...] I just stay, like, perpetually really uncomfortable and nervous throughout the entire meal. I'm like, 'What if there's peanuts in something someone's eating? What if they're too close to me? What if it makes me sick? What if I start having a severe reaction to it?'" (P04, I)*

Feeling isolated from peers who did not have nut allergy was common, particularly when socialising around food: *"Everyone has a Chinese Thursday and I'm like, 'Okay, I'll just go to Greggs.'" (P21, I). "One of the annoyances is the smug looks from your friends when they've got a cake and you don't."* (P33, FG). A further point of commonality across the participants related to problems they faced explaining their allergies to their peers. At one end of the spectrum, participants felt their non-allergic peers did not take their allergies seriously or appreciate the risks they lived with on a daily basis:

*"Half the people in the class don't believe that I could have such a severe allergic reaction. They just think I'm lying."* (P07, FG)

*"I've read so many stories of people dying purely because they were too sick to take their adrenaline and no one around them knew how to do it. [...] [Allergy is] this massive, massive thing that makes you really isolated from other people."* (P04, I)

At the other end of the spectrum participants reported being bullied, sometimes dangerously so, for having allergies:

*"I have a friend who is also allergic to nuts and jokingly one of my friends was eating nuts that he was allergic to [...] He was eating them and one of my friends took one and ran off and apparently he gave it to an upper 6th member and told him to put it down his back [...] So he went over and put it down his back [...] people don't really understand how serious things like that can be."* (P22, FG)



While stories like this were more extreme, feelings of being isolated from those who do not understand the daily anxieties of living with severe food allergy were common and clearly felt as a great burden for many participants. However, in having an unusual opportunity to meet with others with common experience they were able to exchange such stories, seek solace in one-another and share strategies for managing their condition and dealing with peer and family attitudes.

### **Educating Others**

A protective factor against the sorts of misunderstandings and deliberate attacks described above was having a supportive peer network. Several participants described the comfort they drew from understanding friends and people around them who knew what to do in the event of a reaction:

*"I know a lot of my friends, when they found out I had an allergy they've gone out and researched it and looked into it and stuff like that because, you know, they wanted to know what they could and couldn't do. My partner [...] Googled it and he was like, 'Is it safe to eat peanuts if my girlfriend's allergic to them?' The general consensus was 'no' so he's just stopped eating them."* (P04, I)

*"I had one friend a while ago [...] I taught him [about anaphylaxis] [...] we went to the cinema a few years ago, and pretty much the first thing he did when we got there was say, 'I just want to check. What do I do if you have a reaction of some kind?'"* (P33, FG)

However, telling friends about anaphylaxis did not come easily to all. Many felt their friends were not as well-informed as they should be. It was felt that it *"takes a lot of effort to teach all my friends. Some of my friends know how to use the injector though."* (P01, S). Another noted that their friends *"know the basics but probably forgot the technicalities"* (P07, S). In response to these issues, several participants expressed that the React app had been a useful tool to help them share about anaphylaxis with their peers and had facilitated the development of these protective support networks: *"The React app was easy to use and understand, it was an easier way of teaching my friends."* (P10, S). Others went on to explain:

*"I think it was good how it had videos of a live anaphylactic shock, so [...] if you didn't know what you were doing, you could see how to deal with it in different scenarios."* (P37, FG)

*"It was good that it helped me explain to people how to use my EpiPen [...] You'll be like, 'You don't need to take someone's trousers off.' for instance. They don't believe me. They think that I'm just being shy or something. [...] having an actual official looking app that told them you don't need to take people's pants off, that helped [...] I feel like people trust an application more than they trust me, which sounds really bad but it's true."* (P04, I)

Participants explained they would use the videos on the app as a way of visually talking through with their friends how to recognise a reaction, how to use an auto-injector device and then informally 'test' them on this knowledge. Often, this was done by showing them the videos via the participants' mobile phone. However, some participants referred to the sharable design of the React app and how this was valued as then friends could take this "knowledge" with them:

*"React was easy to share with people [...] they all had like their phones and like QR Readers on it so they're, 'Oh, we'll have a look.' [...] Check it every now and again so they could remind*

*themselves [...] it's like easier than having to carry like the training [auto-injector] round and saying, 'This is what you have to do with it.' It would be a bit easier for them to be able to see like on their phones what they have to do."* (P15, FG)

Though a difficult process for many, building a supportive peer network is very important for adolescents living with nut allergy. Our education package gave participants tools to share important messages about their condition with their peers. The app in particular was a source of portable information that friends would trust and use to learn about their condition, with video an important component of this.

### **Risk Taking and Forgetfulness**

Participants reported that living risk free with nut allergy was not possible, or perhaps even desirable. Managing risk was a cornerstone of day-to-day life with allergy. Indeed, despite going through the educational intervention (and with many continuing to occasionally access the app), participants explained how they would engage in risk taking behaviours, such as deliberately not always carrying their adrenaline. One reported that in the past she had done this out of a need to reject her auto-injector as a talisman of her allergy:

*"I was, you know, 'I'm super independent. I want to go out on my own, I don't want to take my EpiPen with me because I'm sick to death of the sight of it.' [...] Luckily, the few times I managed to get out the house without it, I did not have a reaction and die."* (P04, I)

However, for most there was a considered risk assessment into whether they felt there was a need to carry their adrenaline for a particular situation and whether this outweighed the inconvenience of having to carry the device:

*"Yes. Occasionally, like if I'm going to a friend's house, I might trust them and I know they're not going to give me something that they know would be bad, then I might leave it at home."* (P33, FG)

Participants also described managed risk taking when it came to deciding whether or not to consume certain products. They explained that if one was to refuse to eat anything that packaging suggested "may contain nuts" then that would result in a severely restricted diet and was not necessary:

*"It's not really risking it, but I'll normally eat stuff if it says, 'may contain traces of nuts' [...] if it says something like 'may contain traces of peanuts' or if it's got peanuts in it it's just like, 'Nope. Will not.'" (P04, I)*

*"Unless it specifically says 'peanuts', then the likelihood is I'll eat it."* (P14, FG)

Participants described the React app as a safe place to explore risk taking and the outcomes of such behaviour: *"Tried getting [the app scenarios] wrong a few times just to see."* (P09, FU2). While these examples highlight situations where participants explicitly engaged in risk taking, there was also an admission by many that they often just forgot to take their adrenaline devices with them. This included when going out with friends, or going to school or college, situations that might include high risk of exposure to nuts:

*"I can count [...] the number of times this week I've gone out without it [...] I always forget."* (P15, FG)

*"I've forgotten it one or two times to school if I've swapped them round. If [...] I've swapped it into my weekend bag and I've then*

*forgotten to put it in my school bag on the way to school. Then I'm like, 'Don't come near me. Everyone stay away.'"* (P21, I)

However, participants found that “[React was helpful] for refreshing my memory” (P39, S) and the app was, “a resource that you can turn to” (P36, FU1). One participant remarked that the app “helped remind me to bring my EpiPen.” (P22, FU2).

Managed risk taking is a feature of life with severe allergy for adolescents. Our education package helped the participants to feel informed about the risks that they face daily and to manage these risks safely. For those that used it, the app was an ever-present resource that could remind them of ideal self-management behaviours. However, there remain areas of risk that are unintentional, such as forgetting to carry their adrenaline auto-injectors. This highlights the need for systems to assist adolescents with remembering to carry their adrenaline, as education may not be enough to close this gap.

## DISCUSSION

This is, to our knowledge, the only field study of an educational intervention with adolescents living with the risk of anaphylaxis from nut allergy. Our findings demonstrate that our approach has long-lasting impact on the confidence and auto-injector carriage of this population. Additionally, those participants that reported using the React app had better anaphylaxis knowledge at 12 months and confidence at 36 months compared to baseline and to those who did not use the app. In the following we reflect on our findings and consider why the intervention, and the React app specifically, were so successful.

### Video-based Education and Sharing

Young people living with nut allergy must learn how to control their environment to protect themselves from nut exposure. However, not all adolescents can remember the last severe allergic reaction they had, as their last reaction may have been many years ago and parents are likely to keep the home as a protected environment. The React videos helped open their eyes to their susceptibility to a potentially severe condition [57] by showing them what a reaction might look like and how to respond appropriately to it. Repeated exposure to branching video-based narratives in the React app may have enhanced users' anaphylaxis knowledge by allowing them to see the outcomes of different management approaches, leading to better confidence. By framing the videos within peer group discussion we were able to encourage the young people to share personal experiences of living with allergy and helped them to see that there were others living with the same issues. Furthermore, the videos were engaging, memorable and, through the app, a convenient method of educating friends about anaphylaxis. Participants developed well-informed and supportive peer networks that understood the potential severity of anaphylaxis and were equipped to assist in an emergency.

### Reducing Burden Through Confidence and Networking

We know food allergy has a considerable effect on the quality of life of adolescents [4]. Adolescents with greater responsibility for self-care of their food allergy may have

greater anxiety [3]. One concern on embarking on this project was that in the process of making participants more aware of their allergy we would negatively impact their psychological well-being. While our study did not measure anxiety directly, our participants' measured quality of life improved, they reported an improved sense of control over their allergy and better confidence in managing reactions. The quality of life improvement was most marked in the Emotional Impact subscale of the FAQLQ-TF (items relate to fear of consuming allergens, fear of reactions and the burden of carrying adrenaline). By increasing participants' belief in their own capabilities we may have improved their self-efficacy [7], reducing the emotional burden of their allergy. The Health Belief Model suggests that we may have assisted this change through participants better appreciating the risks of their illness and understanding ideal responses to reduce these risks [57]. It was also clear from our qualitative work that many of the participants felt better equipped to share the burden of their allergy with friends, using the app to demonstrate to them what an anaphylactic reaction looks like, how to use their auto-injector devices and through sharing their personal allergy information. Thus, the React app and their improved knowledge and skills, may also have contributed to the observed improvement in quality of life.

### Adrenaline Auto-injector Carriage

Unlike other described systems to support those living with allergies [16, 18, 32], React (and the associated education session) aimed to improve adolescents' ability to self-care by empowering them to make more informed risk assessments. As well as supporting feelings of greater awareness and self-care, our intervention improved carriage of auto-injectors. As noted, non-carriage of these devices is known to be a factor in deaths from anaphylaxis [10] and evidence shows that not just knowledge, but also perceived risk and confidence influence adolescents' decision making when deciding to carry adrenaline [33]. Few previous interventions have shown an improvement in auto-injector carriage [64], with previously described rates in adolescents of less than 50% “always” carrying their devices [33]. We have shown a highly significant improvement in participants' auto-injector carriage, which may be related to an increased sense of the need to carry it and a perceived reduction in the burden of doing so. However, some participants still forget to carry adrenaline. We do not think that the observed improvement in carriage is a natural part of growing older with allergy as other work suggests that <30% of at risk adults carry auto-injectors [63]. Other work by this study group (manuscript in review) suggests that similar adolescents not receiving our intervention do not show the same improvement in auto-injector carriage over time.

### Limitations

There are limitations to our work. The React videos did not resonate with all our participants and were unable to capture the full variety of anaphylaxis presentations and responses to treatment. By framing the videos within group discussion we were able to address some concerns, but this is not possible

for the videos in the app. One solution would be to create videos with a wider variety of presentations. This would be time consuming, resource-intensive and potentially still leave challenges with resonance with personal experiences. The uptake of the app was just under 50% of those seen at 12-month follow-up. This was partly due to technical limitations of our approach. Some adolescents did not have mobile data plans so had to rely on Wi-Fi, which was not available in all situations. The web-based app allowed multiple brands of device to access it, but participants did not remember how to access it when changing phones or after a factory reset. Furthermore, there were a number of participants lost to follow-up over the course of the study, with just over 50% captured in the survey. It is possible that there is loss to follow-up bias, with those more likely to perform well more likely to continue study engagement. Additionally, compared with other work [40], we have a lack of detailed app usage analytics. This is partly due to ethical constraints but would need to be addressed in future work.

### Design Opportunities

While being overall successful, our findings also highlight a number of further opportunities for designing technology to support adolescents at risk of anaphylaxis, and young people living with chronic health conditions more generally.

First, our work highlights the potential for video-based educational interventions. Memorable video narratives that draw on literature, clinical and personal experience may have similar impact in conditions such as asthma and diabetes (where emergency treatment must be carried and used appropriately). The novel app-based branching narratives used in this work allowed participants to explore safely the outcomes of different self-management steps, reinforcing key messages and essential behaviours. However, we also saw how such video content can reproduce assumptive and stereotypical situations and experiences. One direction for future design work might therefore be to support the creation of user-generated videos and media that layer on top of videos like those produced for our intervention [59]. This might promote opportunities for young people to 'react' to videos, to share their own version of similar events, and scaffold wider diversity and multiplicity in the types of experiences represented in interventions like these.

Second, the React app contained a simple method of sharing with friends. By working through the anaphylaxis narratives on the app, participants could help their friends to explore how they could help them both day to day and in a crisis. Unlike, for example, an online support network, using the app to physically interact with those close to them helped our participants to build up local support networks of understanding and informed peers. This resonates with work by Glasemann et al. with young people living with diabetes [27], in which the authors suggest that mobile health technology may have a role in promoting a social learning experience. Further opportunity exists to explore how peer support may enhance self-care, using systems to share

knowledge beyond the group education session [26]. As such, as recent work has highlighted [66], opportunities exist here to bridge the physical peer support group with those supported by online environments and mobile technologies. We might imagine these could be supported in ways particular to anaphylaxis. For example, to address issues about forgetting adrenaline auto-injectors, Bluetooth technology could be used to pair devices with their owner's smartphone and provide sensitive reminders to carry adrenaline to the phone or send prompts to the peer network, who could then encourage them to carry their device.

Finally, there are opportunities to empower adolescents with nut allergy to change not only their own behaviour but the attitudes and behaviour of the general public. Many of our participants reported how negative attitudes of others caused them distress or were, in the worst cases, endangering them. This cohort of young people are now experts in their own condition and it is important to explore how they could be supported to put pressure on the food industry (and the public in general) to be more considerate and considered in their approach to allergies. Tools like NutFree [26] are important here, but only if they support changes in environment and attitude towards those with these life-threatening conditions.

### CONCLUSIONS

Our research has shown that adolescents living with severe nut allergy can learn how to better self-care through a peer group-based intervention involving video narrative and a mobile application. This has had long-term effects that are likely to persist into adulthood and improve the safety of this population. Further work is needed to explore how adolescents can be empowered to harness supportive peer networks and influence general public and industry attitudes to severe allergies. Working with young people who live with the burden of anaphylaxis has shown us that this burden should be shared not only by families and friends, but that wider society has a crucial role to play too.

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